# The Power of Partnership:
# Meeting Today's MCH Challenges through Partnerships
# MCH Training Program

## Family-Centered Curricula Workgroup
## October 5–6, 2004

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**Introduction and Charge**

The *National MCH Training Plan* (obj. 2.3, activity 1) calls for "a set of specific activities for MCHB to undertake, designed to ensure that all MCH trainees receive comprehensive training in family-centered services." The goal is to have family-centered care incorporated in all HRSA training programs goal by 2008.

Family-centered curricula (FCC) are critical to mission of HRSA and must be viewed as a part of the strategic process and incorporated into all of the training programs presently funded. The principle of family-centered care should permeate all aspects of education for staff—not just a module.

The design of policy needs to include families as equal partners. Family-centered initiatives should further focus upon the needs of the individual as well as the family with the understanding these needs must be customized and revised based upon the various life stages. Transitions occur at many times during the lifespan not just at diagnosis.

The workgroup was encouraged by Albert Hergenroeder to brainstorm some ideas to meet this challenge. He invited all the participants to share freely their experiences and suggestions on how to effectively incorporate family-centered curricula into the various training programs funded by MCHB.

## Working with Families

The participants offered various suggestions on how to solicit the support and participation of the family, including providing financial compensation for family members. This factor emphasizes the importance and commitment of the family's contribution to the design and development of the program. Working with a paid parent has proven very helpful. In addition, some programs have people that serve a dual role as both family and faculty. This ensures a continual communication and input process for the development of the curriculum. For example, one participant mentioned that their review board includes paid parents' input in both evaluation and design phase of care.

To ensure that trainees receive hands-on experience, programs should require trainees to make home visits to learn how to work with families. Direct observation is very important for evaluation of care. For example, one nursing program was discussed that used home visits to not only gather clinical information, but also to learn about the aspirations of the parent and child.

To develop a full perspective of how the entire family is affected, it is necessary to view the family in its surrounding community. Family and community education are very important to ensure effective service delivery.

The group challenged the definition of family and discussed how the term *family* should be broadly defined. MCH programs should consider parents as care givers and others beyond the immediate family, such as extended family and friends. There are also nontraditional families.

A case study was presented by one of the facilitators to highlight the importance of family-centered curricula. A young child had a complicated care regimen involving multiple treatments each week. The staff was upset with the care of the child because of numerous missed appointments and treatments. Further investigation revealed that there were numerous barriers to the child receiving proper medical treatments. These barriers included other siblings with special needs, an unemployed father, and a mother who assumed the primary financial responsibility for the family income.

## LEND, LEARN, and LEAH Programs

The facilitators led a discussion focused on the LEND, LEARN, and LEAH programs. The discussion also touched on the certification program, Project DOC, and the Nurse Midwifery program.

Under the LEND program, actual families are introduced as learning tools for other families; however, HIPAA privacy requirements are honored. FCC is not just a module; it is incorporated as an overarching principle. The participants recommended that an evaluation tool should be developed to gauge whether a trainee has incorporated family-centered care.

Pre- and post-tests are completed for competency assurance. Web-based competencies are also available for learning opportunities. Research modules are validated by family faculty feedback (FFF) given from the family's perspective.

Regarding the LEARN program, the participants discussed how to incorporate a family advisory board into programs to ensure that a family-centered focus is maintained in curricula. One participant shared the how a family advisory board may be managed. The board meets annually and case reports are provided for each member prior to the meeting for review. Multiple perspectives are given on each report. Minutes are recorded of the actual meeting. Attendance and participation are voluntary. The direction of the program is a major point of discussion, and feedback from families regarding their needs is critical. In some cases, selected family cases are chosen for more in-depth study.

For certification programs, review boards may include paid parents' input in both evaluation and design phase. Continuity and observation are both very important.

In the Nurse Midwifery program, all clinical encounters include an assessment of whether a family-centered approach is being used in counseling and planning. Families are requested to attend a partner's monthly meeting in order to discuss the delivery of health care.

For Project DOC, physicians visit families at their homes. No clinical care is provided during these visits. The University of Massachusetts did a project on family-centered care. It is important to realize that transitions occur at many different times, not just as the time of diagnosis of the child.

The participants came up with myriad suggestions about how to incorporate a family-centered curriculum into an overall training program. They noted the diversity of the various training programs in terms of funding levels and whether the programs are academic or clinical in nature.

*Suggested Ways to Incorporate Family-Centered Curricula into Training Programs:*

- Home visits
- Objective structured clinical examinations (OSCEs)
- Lecture
- Family advisory board
- Home visits/community-based visits
- Family assessments
- Escorting families to visits
- Families as trainees
- Families included in all aspects of continuing education
- Solution-focused learning
- Parent-to-parent projects
- Family support activities
- Partnering with families
- Previous clients talking about transitions previously experienced
- Families paid for input as are other professionals at meeting (equitable reimbursement)
- Plan of care to include evaluation tools, references, and research principles
- Family education days
- Family's feedback on trainees

- Customer satisfaction

*Resources Available to Support MCH Programs in Developing Family-Centered Curriculum:*
- Family Voices
- Florida Institute for Family Involvement (FIFI
- Project DOC
- Institute for Child Health Policy
- Institute for Family Centered Care (www.familycenteredcare.org)

Developing an effective evaluation system for evidence-based success stories is critical for demonstrating the effectiveness of a family-centered curriculum. The participants brainstormed about the tools available to help programs develop appropriate evaluation systems for family-centered curricula.

*Tools for Developing an Evaluation System:*
- Students' reports on family-centered care in clinical settings
- Student evaluation of delivered care (clinical evaluation)
- Family feedback on the effectiveness of didactic training
- Clinical outcomes versus family-centered outcomes; look at both perspectives
- Effectiveness of didactic education as appropriate
- Effectiveness of trainers
- Peer-reviewed publication research
- Encourage evidence-based, family-centered approach
- Families as teachers

In an effort to define or standardize the components of a family-centered curriculum, the group discussed various topics or subjects that should be included. Among the components identified were continuous quality assurance; content; family theory; assessment; identification of who is to be involved; designation of roles and rules; identification of subsystems; boundaries; and the external environment.

## 100% Family-Centered Care?

There was some discussion about whether the 100% FCC goal is reasonable for all HRSA programs. Three years seems like a rather ambitious goal; however, it may be necessary to look at the level of the programs because, for example, certificate programs have fewer resources than PPC or LEND. Several ideas were offered about barriers to the 100% FCC goal and what would be minimal standards for HRSA programs.

*Needs and Barriers for the 100% FCC Goal:*
- Need for an appropriate taxonomic system;
- Curriculum design, development, and implementation;
- Awareness (action oriented/ knowledge);
- Some programs do not have the capacity to incorporate FCC activities in every step;

- Family involvement must the needs of the program and trainees
- Family must be included in all of the curriculum development.
- Family needs are constantly changing; therefore, it is difficult to develop a program by viewing only one point in time.
- Is methodology present to evaluate programs?
- The curriculum must be tied to the various developmental stages including biomedical/biosocial evaluations of treatment from both families and staff.

## Conclusions

*Guiding Principles Suggested by the Workgroup:*

- End users (children, youth, adults, and families) must be engaged at all program phases (planning, implementation, evaluation).
- The family is the center of the team.
- The family is self-defined.
- Partnership and collaboration are essential.
- Family-centered care should be strength-based or asset-based.
- Family-centered care should promote family resilience.
- Support, encourage, and empower families.
- Treat families with dignity and respect.
- Embrace cultural and linguistic competence.
- Families should be paid for their input just as any professionals would be (equitable reimbursement).

*MCHB Wish List:*

- Increase family involvement in all processes (present and future).
- Explore and gather programs that are opportunities for family-centered care (e.g., NCFR, specialty groups [consumer and professional], Division of Nursing of HRSA, and National Institutes of Health).
- Develop a Website, electronic bulletin board, or searchable database to collect and make available internal and external input for grantees and program staff.
- Encourage grantees to evaluate their own programs and publish the data to expand the available research database.
- Dedicate MCHB monies for research into the effects of family involvement on trainee learning (curriculum evaluation).
- Involve families in the next planning session, such as the one we are involved with today.
- Develop a self-assessment tool or form for trainees, programs, and faculty.

The workgroup also suggested several ways to work with families in training programs by using or taking advantage of existing models, bringing in families as members of curriculum team, and making a real commitment to family-centered care by starting small and building from there.